Understanding of Multiple Sclerosis Diagnosis, Disease Progression and Clinical Classifications from Adult and Pediatric Patient Perspectives

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## Introduction

- Diagnosis of multiple sclerosis (MS) is life-changing for patients. The impact of diagnosis may be particularly pronounced for those diagnosed at a younger age (< 30 years)
- There is growing recognition of the need to understand patients' perspectives on MS progression, and the use of clear terminology may facilitate communication between patients and healthcare professionals (HCPs)
- We explored understanding of MS diagnosis, progression and disease classification from the patient perspective, using insights direct from 4 patients with different disease durations to help improve understanding of MS

## Methodology

- In-depth, qualitative interviews with 3 patients diagnosed with MS as adults and 1 patient diagnosed during adolescence: Kristen Fetty ([KF] relapsing-remitting MS [RRMS], for 1 year), Jeri Burtchell ([JB] RRMS, for 18 years), Kit Minden ([KiM] secondary progressive MS [SPMS], for 6 years) and Katelyn Miller ([KaM] RRMS, for 12 years – first diagnosed aged 13 years)
- For these interviews, pediatric patients were regarded as those aged under 18 years and adults as those aged 18 years or older

## Results

# MS diagnosis

#### Clinical practice: MS diagnosis

- Revisions to 2010 McDonald criteria permitted diagnosis of MS based on a single magnetic resonance imaging (MRI) scan, accelerating the diagnostic process<sup>1</sup>
- Recent development of these criteria will facilitate diagnosis of patients<sup>2</sup>

#### Patients' perspectives

- An MS diagnosis can elicit feelings of shock, anger, or even relief. Such emotions may be exacerbated by the fact that many patients endure a long period of uncertainty pre-diagnosis
  - "10 years [before my diagnosis], I had had issues with my arm falling asleep ... a friend's GP said 'you have MS, there's nothing we can do for you'" (JB)

"When I eventually got the diagnosis, I thought: I've been here before and it's not true. The second time could not have been more different ... my doctor did everything he could to rule out MS. I got the definite diagnosis a couple of months later" (JB)

> "The first time I had numbness I was 16 and it lasted a few days." I would experience numbness on and off for a couple of hours a day, but I thought nothing of it" (KF)

"I was 20 years old when I was diagnosed and I was terrified ... I was referred to a neurologist; they took MRIs of my brain and spine and they saw lesions ... It took about 3 or 4 months to get a diagnosis" (KF)

"When I got the diagnosis they couldn't do much for me [...] although I didn't expect it, it clicked – it was suddenly very real" (KiM)

"I first got symptoms when I was 23. Half my body was numb; I had had a fall, and my limbs were spasming" (KiM)

"I was diagnosed at 13. It started with numbness and tingling; my symptoms were brushed off. It was a very confusing and difficult time; I was told I was making it up, which made me feel worse and depressed" (KaM)

> "I was diagnosed right in the middle of the school year. I had to pull out of school because I felt so bad. I missed several months and had to finish the year at home – but I hated it, I wanted to go to school" (KaM)

"I've been on several injections and had side effects – they made me feel like I was sick and I ached from bruising. I refused to take them at one point; my parents thought I was, but I wasn't. This made my MS worse, until I was forced to accept that I had to get on treatment. I used to pray for a pill – it would have been a lot easier, I would have taken that" (KaM)

## MS phenotypes

 In 2013, MS was classified into distinct phenotypes, with sub-classifications for disease activity and progression (Table 1)2-4

#### Table 1. Phenotype descriptions for RRMS and progressive MS<sup>2-4</sup>

#### A syndrome such as optic neuritis, brain stem/ cerebellar dysfunction or partial myelitis Characteristics of inflammatory demyelination are present, but McDonald 2010 criteria of dissemination in time are yet to be fulfilled MRI evidence of dissemination in space, as well Active<sup>a</sup> as gadolinium-enhancing and non-enhancing T2 lesions on a single MRI scan and/or a Not active subsequent event **Progressive MS** Active, a with progression b Progressive accumulation of disability from onset Active, a without progression Not active, with progression<sup>b</sup> Progressive disease Not active, without progression

<sup>a</sup>Clinical relapses and/or MRI activity (gadolinium-enhancing MRI lesions or new/enlarged T2 lesions) assessed at least annually

(stable disease)

bMeasured by clinical evaluation at least once yearly

CIS, clinically isolated syndrome; MRI, magnetic resonance imaging; MS, multiple sclerosis; PPMS, primary progressive multiple sclerosis; RRMS, relapsing-remitting multiple sclerosis; SPMS, secondary progressive multiple sclerosis

## Recognizing, diagnosing and understanding disease progression

Progressive accumulation of disability

after initial relapsing course

### Clinical practice: MS progression

- Recognizing and diagnosing MS progression is a challenge
- No universal definition of SPMS<sup>5</sup>
- Not known which patients will transition to SPMS
- Normal age-related changes overlap with symptoms of MS<sup>6</sup>
- Diagnosis of SPMS may lead to withdrawal of treatment
- HCPs may therefore be cautious in applying the SPMS label to patients<sup>7</sup>
- Engaging with patients and a collaborative approach to care are essential for optimum disease management<sup>8</sup>

#### Patients' perspectives

Although the 2013 classification terminology was beneficial for HCPs, it is not known whether patients understand the terms or find them useful

"It's confusing ... The classifications group us, but "I felt overwhelmed and was everyone is different. Some people have a hard time very angry. It was hard for my parents too" (KaM) believing their diagnosis because the classifications don't relate to the realities of their lives" (KiM) "When I was diagnosed in

"Once I was diagnosed, I was ready to get on treatment! I wanted to be a normal kid" (KaM) MS was – I confused it with "I didn't even know that there were different types of MS" (KF)

 Having a good knowledge of MS may help patients and their families; however, support and information are often limited<sup>9</sup>

"I researched MS online, but the Internet was so new that finding good sources of information was not easy. [Initially] I mostly learned through anecdotes and conversations with other patients in online forums" (JB)

"Until I joined a clinical study, most of my information came from MS groups, pamphlets (which weren't particularly patient friendly) and online information" (JB)

"The books tell us a lot about MS, but not about how to live with MS" (KiM)

"I don't have much understanding – I do my research, but I could do more" (KaM)

1999, I didn't know what

muscular dystrophy" (JB)

## MS as a disease spectrum

this, we might feel connected" (JB)

 Based on patient insights, it may be helpful for patient understanding to describe MS progression in terms of a disease spectrum (Figure 1)

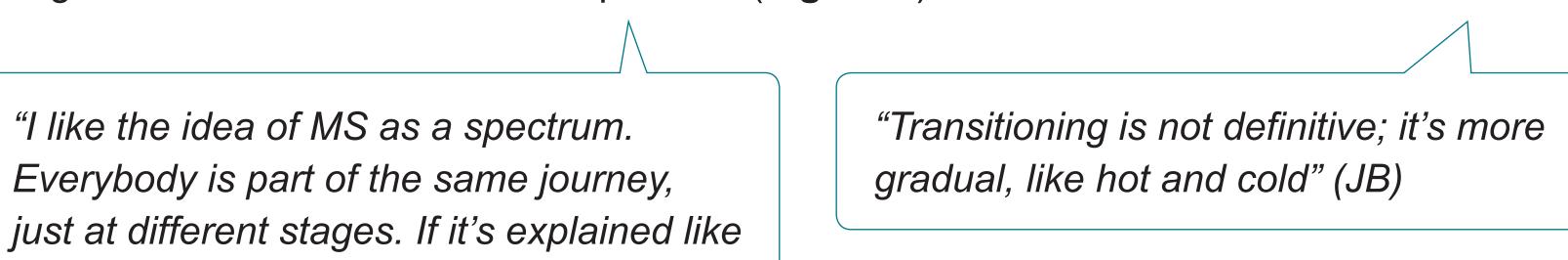
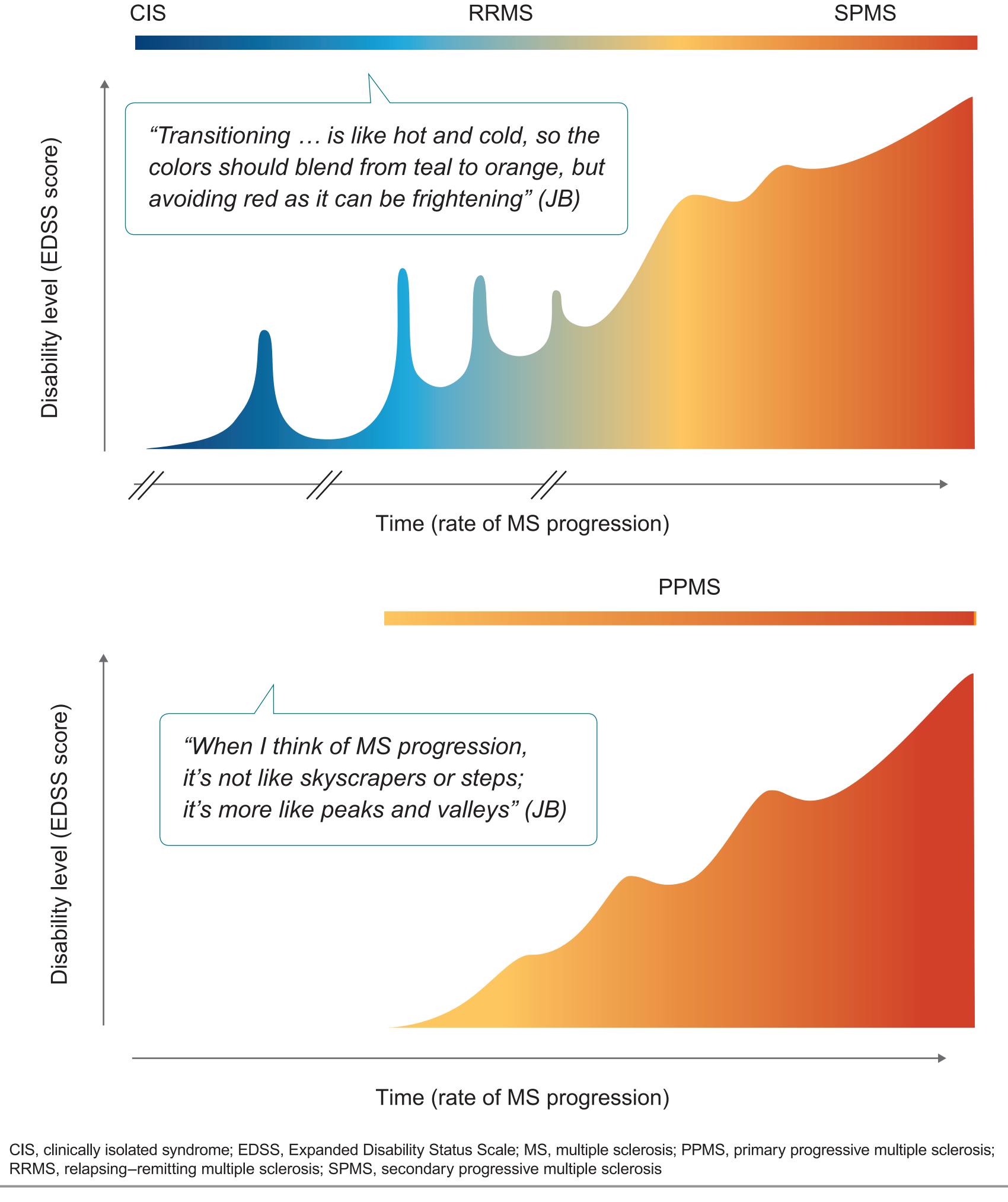


Figure 1. Schematic illustrating patients' perspectives on MS progression as a disease spectrum rather than as distinct phenotypes



#### Clinical practice: MS classification

- Redefining MS as part of a spectrum may not be suitable for HCPs because the clinical classifications underpin routine care<sup>2-4</sup>
- However, it may be helpful for HCPs to describe MS as a spectrum when talking to their patients

## Living with MS and managing the transition to SPMS

#### Patients' perspectives

Patients with MS must overcome many challenges

time and it became really difficult" (KF)

"I was a graphic artist and had a "I struggled to work as a tutor because of print shop for 10 years; when I was cognitive fog ... It's my job to make sure that everyone is OK. Yet I can't do that" (KiM) diagnosed, I had to close it" (JB) "I had to change jobs. I worked in a "I'm aware that the disease can store where I was on my feet the whole progress and that disability may happen

I accepted that a long time ago" (KaM)

- Regular patient check-ups help ensure early detection of changes and allow management plans to be reviewed
- Good patient–HCP relationships are key to receiving appropriate support

"I go to my clinic to have an MRI every 6 months; they also do the 25-Foot Walk Test, 9-Hole Peg Test, and cognitive and vision checks" (KF)

"I try to get plenty of rest and pace myself, and recognize when I'm overdoing it" (JB)

Internet and social media provide both practical and moral support for patients<sup>10,11</sup>

"Almost instantly others from around the world commented and shared their experiences, giving me feedback l needed to make decisions" (JB)

"People were also sharing about how they were switching MS medications when theirs 'quit working' for them. The next time I saw my neurologist I asked him about switching" (JB)

## Clinical practice: managing MS

- In the USA, 15 disease-modifying therapies are approved for relapsing forms of MS.<sup>12</sup> In contrast, only mitoxantrone is licensed specifically for SPMS, although it is rarely used owing to concerns over cardiac toxicity and leukemia 12,13
- Non-pharmacological interventions can improve outcomes<sup>14</sup>

"Food plays an important role in how I feel. I used to get horrible gastrointestinal issues, but these stopped when I gave up dairy. And on days when I eat fewer sweet things, I have less spasticity at night" (JB)

"I exercise right, I eat right. I always appreciate advice and guidance. My faith is also important to me, which helps" (KaM)

"I received advice on exercises from a physical therapist. I stopped eating gluten and cut down on dairy [...] I felt like a lot of the disease progression had slowed" (KiM)

### Conclusions

- Although revised criteria help neurologists diagnose MS rapidly, patients can experience long delays before being diagnosed and receiving treatment
- Patients must overcome many challenges when diagnosed with MS, especially if diagnosis takes place when the patient is young
- Improved communication between patients and HCPs about MS and its progression that reflects both patient and HCP perspectives may be helpful in managing the disease8
- Current MS classification systems may be more useful to HCPs than to patients
- For patients, it may be appropriate to describe MS as part of a disease spectrum

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Disclaimer

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